THE PMLD AMBIGUITY

Articulating the Life-Worlds of Children with Profound and Multiple Learning Disabilities

BEN SIMMONS AND DEBBIE WATSON

KARNAC

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For Gillian, Rosalie, and Caleb—for enriching my life beyond measure and for the abundance of love and support

—BS

For Neil, Charlie, and Will—with love and thanks for your patience and support as ever

—DW

CONTENTS

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PREFACE

Children with profound and multiple learning disabilities (PMLD) are said to experience the severest of cognitive impairments which typically stem from extensive neurological damage (Carnaby, 2007). The abilities of such children are often compared to those of the neonate or infant insofar as children with PMLD are described as operating at the earliest, preverbal stages of development (Coupe O'Kane & Goldbart, 1998). It is argued that the profound developmental delay of children with PMLD precludes them from engaging in most social and educational environments (Foreman et al., 2004). Subsequently, such children are typically educated in special schools (Salt, 2010).

This book takes an alternative perspective which challenges the very idea of "PMLD" itself and, consequently, what constitutes appropriate educational provision for children described as having PMLD. We take the position that the dominant conceptual approaches used to understand children with PMLD (i.e., behaviourist psychology and cognitive psychology) are too simplistic, overly reductive, and (when used exclusively) essentially objectifying. These approaches privilege only a small cluster of behaviours said to be indicative of the presence or absence of children's conscious awareness of self, other, and surrounding world. By privileging only a limited number of behaviours

deemed to be meaningful (or not), the PMLD literature overlooks the complex, dynamic, and varied forms of shared and personal experience.

In an attempt to address this situation, this book presents alternative ways of thinking about, experiencing, and engaging with children described as having PMLD. This aim is achieved through several steps. Chapter One explores the concept of PMLD, first through the introduction of contemporary terminology and definitions. We then provide a thematic review of the PMLD literature and identify key issues relating to how the concept of PMLD is described, constructed and understood, and how this relates to policy and practice for children described as having PMLD. We draw from a range of theoretical and empirical perspectives in order to grasp the main issues discussed, with the purpose of locating our approach to thinking about children with PMLD. During the literature review we also engage with research about adults with PMLD (particularly with regards to deinstitutionalisation and community participation). Whilst the focus of the book is on children with PMLD within educational contexts, the theme of exclusion identified in the adult literature is arguably just as important to children in light of minimal opportunities for educational inclusion.

In Chapters Two and Three we deconstruct the dominant psychological perspectives used by academics who conduct research with people with PMLD. We do this in order to illuminate the core ideas and presuppositions that guide interpretation of people with PMLD and shape specialist practice. In these chapters we use the term "people" instead of "children" as this is consistent with the literature we review. In Chapter Two we look at the core concepts found in behaviourism—that is, classical conditioning theory (Watson, 1913) and operant conditioning theory (Skinner, 1986). We then explore how these concepts have shaped several decades of research concerned with conditioning the behaviours of people with PMLD. During the review of the behaviourist literature we also identify how contemporary researchers have started moving away from a purely "externalist" ontology toward grasping how events theorised as "internal" to people with PMLD, such as behaviour states (Guess et al., 1993), mediate the efficacy of conditioning programmes. Further, we note growing interest in how operant conditioning procedures can lead to people with PMLD developing contingency awareness (or knowledge of cause-effect relationships) (Saunders et al., 2003b). We

also describe how conditioning techniques have been used to increase the "happiness" of people with PMLD.

In Chapter Three we deconstruct the cognitivist literature as it relates to children with PMLD. Researchers influenced by cognitivism draw from a wealth of studies about infant–parent interactions (e.g., Bates et al., 1975; Schaffer, 1971a; Trevarthen, 1979) in order to map out the "normal" developmental trajectories of children without disabilities, and to illuminate the mechanisms through which children typically develop. We begin the chapter by exploring key ideas at the heart of this work. What we present is not a coherent theory of child development, but a range of perspectives which are in some respects radically opposed to each other, particularly with regard to the nature and emergence of intersubjectivity and joint attention. After identifying these tensions we then explore how the work has influenced school assessment strategies for children with PMLD—that is, the early communication assessment (Coupe O'Kane & Goldbart, 1998). We also look at how cognitivism has influenced intervention strategies, such as Intensive Interaction (Nind & Hewett, 1988; 1994; 2001) and responsive environments (Ware, 1994; 2003).

In Chapter Four we break away from traditional psychological approaches and critically engage with an alternative approach to thinking about consciousness and (embodied) cognition found in phenomenology (Merleau-Ponty, 1963; 2002). The purpose of this engagement is to explore the ways in which non-traditional concepts challenge traditional understandings and offer potential for rethinking the awareness and abilities of children with PMLD. In the chapter we describe the notion of the "life-world" (Husserl, 1970) as a level of awareness or experience that is not found in descriptions of children with PMLD informed by behaviourism and cognitivism. Following Lewis and Staehler (2010) we define the life-world initially as our pre-conceptual experience of the world. Through Lewis and Staehler (2010) we then explore Husserl's (1970) "mature" concept of the life-world, which holds that history and culture (including scientific activities such as psychological research) influence our immediate, pre-thematic, everyday experience. We explore how the life-world is actualised through the body in the world as the vehicle for perception and signification. Through explication of Merleau-Ponty's (2002) notions of the "pre-objective" body (p. 281), "organic thought" (p. 89), and "being-in-the-world" (p. 90), we bridge the mind-body (or rather, cognition-behaviour) dichotomy

of cognitivism and behaviourism and locate children with PMLD in a philosophy that has the power to theorise the agency of children with PMLD in new ways. As a third way between reflex responses and explicit cognition, we find Merleau-Ponty's conceptualisations (1963; 2002) particularly exciting.

In Chapters Five and Six we present a novel research project about how inclusive education could support growth and learning in a young boy with PMLD, called Sam. Specifically, in Chapter Five we describe the research methodology and locate this in wider debates about accessing marginalised voices, particularly the voices of children with PMLD, who are described as having no point of view (Ware, 2004). Chapter Six presents the findings of the study. This presentation serves two purposes. First, the study demonstrates the ways in which freedom to engage with different social milieus allows for different expressions of ability and development. Second, the study "tests" the three perspectives (behaviourist, cognitivist, and phenomenological) by analysing the extent to which each perspective can make Sam's actions intelligible. Analysis demonstrates that a phenomenological perspective has the power to illuminate the research data in new ways. However, analysis also reveals that Sam makes the three different perspectives problematic. Sam resists being "read" from each, insofar as neither perspective can account for Sam's complex behaviours in their entirety. Further, Sam contradicts and obscures dominant understandings in many ways, leading to an ambiguous or shifting identity.

We conclude the book by considering the role of ambiguity in articulating the life-worlds of children with PMLD. At one level we revisit the idea that the actions of children with PMLD can have more than one meaning, and are thus open to different interpretations. This is evidenced by the competing understandings found in the psychological literature that the PMLD research overlooks. At a deeper level we describe ambiguity as an essential feature of the life-worlds of children with PMLD. Following on from the idea that Sam resisted being read from any individual perspective, we theorise the possibility that this is because consciousness and cognition are not capacities contained in the mind (or the brain), but are situated and enacted. In order to understand children with PMLD, we may need to see consciousness and agency as embodied and relational.

CHAPTER ONE

Exploring "PMLD"

The purpose of this chapter is to induct the reader to existing issues reported in the PMLD literature in order that we identify emergent themes that explore the lives of people with PMLD. This process provides valuable insights into the ways in which people with PMLD are regarded, the discourses that surround them, approaches to working with them, and the spaces and gaps within the reporting of people's lives that exist. How these gaps in the PMLD literature provided the space for the study reported here will be elicited as the issues are presented and critiqued.

Whilst we do not claim this to be a systematic review of the available PMLD literature, we explore both research (empirical/theoretical) and practice literatures, and the multiple perspectives contained within them. We also make reference to work published by disability advocacy groups. By surveying the literature in this way we situate this book in a broad context of understandings about children with PMLD and what is (or is not) in their best interests. Inevitably, we have had to make a selection of themes and topics that are included in this discussion, and the overriding concern has been to provide context for the study that is reported in Chapters Five and

Six. This results in some issues not having a robust consideration, such as abuse and neglect, which are important issues but not the focus of this book.

We first describe the terminology and definitions of PMLD operating in the literature. We briefly describe the demographics then discuss literature regarding physical health and mental health. Through this discussion we illuminate common themes such as health inequalities, difficulties with communication, problems accessing the experiences and perspectives of people with PMLD, and negative attitudes about quality or value of life. After exploring the position of families in this debate, we discuss issues related to the inclusive education movement and the extent to which it is realised for children with PMLD. In the educational literature we identify a distinct lack of concepts regarding what inclusion means for children with PMLD, partly stemming from difficulties accessing children's point of view, and partly stemming from a lack of research and opportunities for inclusion nationally. We describe the key theoretical perspectives that inform special educational practice for children with PMLD—that is, behaviourism and cognitivism. We critically analyse the notion of "identity" as it relates to children with PMLD, and how this shapes the way we think about, experience, and engage with such children. The chapter then concludes with a consideration of how concepts of quality of life and wellbeing have been constructed for people with PMLD and the extent to which a perspective emerging from capabilities theory offers a challenge to deficit-based assumptions of the lives of children with PMLD.

It is important to note that a great deal of the literature about people with PMLD is ambiguous in respect of whether it describes children or adults (and often literature refers to both). It is also not clear how children are defined in respect of age and this reflects the definitions explored in the next section whereby PMLD status is often associated with the developmental capacities of infants. For the purposes of this book we define children as encompassing nought to nineteen-year-olds and therefore refer to children and young people. We also attempt to direct the reader to the age group being discussed where it is possible to do so. This developmental definition challenges the identity of people with PMLD (of whatever age) and this is a discussion we return to later in this chapter.

Defining profound and multiple learning disabilities (PMLD)

Research and policy is often plagued with terminological inconsistencies when referring to people with PMLD (PMLD Network, 2001). For example, the UK government white paper *Valuing People* (Department of Health, 2001) contains nine different terms which refer to the population we wish to discuss, including "young people with complex and multiple disabilities" and "the most severely disabled". Researchers at the 12th World Congress of the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSID) used eleven different terms, including "profound multiple disabilities" and "severe intellectual and motor disabilities" (Nakken & Vlaskamp, 2007). In this book we use the term "profound and multiple learning disabilities" because it is consistent with much of the contemporary literature in our home country (UK) (Dawkins, 2009; Lacey, 1998; Young & Lambe, 2011). However, we recognise that historically the UK has preferred to use the term "profound and multiple learning *difficulties*" (rather than disabilities) (Nind, 2007; Salt, 2010; Ware, 2003), and that various other terms are currently used in the UK such as "profound intellectual and multiple disabilities" (Mansell, 2010; Pawlyn & Carnaby, 2009).

Given the varying terminology, it is perhaps not surprising that there is also variation regarding the way "PMLD" is defined (Bellamy et al., 2010; Nakken & Vlaskamp, 2007). However, there are core descriptions common to the published literature. PMLD is a label given to children who are said to experience the severest of impairments to cognition resulting in significant developmental delay (Scope, 2013). The abilities of such children are often compared to those of the neonate or infant insofar as children with PMLD are described as operating at the preverbal stages of development (i.e., the earliest stages of development, which infants are said to pass through during their first year of life) (Burford, 1988; Carnaby, 2004; Coupe O'Kane & Goldbart, 1998; Nind & Hewett, 2001; 1994; Samuel & Pritchard, 2001). Consequently, a range of descriptors are used in the PMLD literature to indicate that such children typically fail to reach particular developmental milestones that some associate with later infancy. For example, children with PMLD are understood as being pre-volitional (they lack free will or agency and cannot move with intent) (Farrell, 2004; Mercieca, 2008); pre-contingency aware (they do not show awareness of cause-effect relationships) (Ware, 1994; 2003); pre-intersubjective (they do not represent other people as

subjects "like me", and cannot differentiate between subject and object); pre-symbolic or pre-intentional (they do not intentionally communicate meaning to others) (Coupe O'Kane & Goldbart, 1998; Goldbart, 1994); stereotypic in behaviour (they display reflexive, non-volitional behaviour) (Tang et al., 2003), and who are at high risk of living in a world of confusion (Cartwright & Wind-Cowie, 2005; Ouvry, 1987).

In addition to profoundly delayed cognitive development, children with PMLD are also said to be prone to a range of other difficulties including physical impairments (Neilson et al., 2000), sensory impairments (Vlaskamp & Cuppen-Fonteine, 2007), mental health difficulties (Fergusson et al., 2008), and complex medical conditions (Pawlyn & Carnaby, 2009). They may also engage in challenging or self-injurious behaviour (Denis et al., 2011; Forster et al., 2011; Lacey, 1998). Against this backdrop, children with PMLD are described as being highly dependent on others for the most rudimentary care needs and are deemed to require a lifetime of support (Mansell, 2010; Petry & Maes, 2007; Tadema & Vlaskamp, 2010).

There are various estimates of the number of children with PMLD in the UK. One recent report suggested that there are 9,000 school-aged pupils identified as having PMLD (Salt, 2010). Another report suggested that there were 14,744 (Emerson, 2009). Despite varying estimates, there is agreement that the number of children with PMLD is rising because of advances in medical treatment (Carpenter, 2007). Between 2004 and 2009 it was estimated the number of children with PMLD rose by an average of 29.7% (DCSF, 2009, in Salt, 2010)—though clearly this estimate must be taken tentatively given the variation in original estimates. Between 2009 and 2026 it is estimated that the number of adults with PMLD in England alone will increase from 16,234 to 22,035 (Emerson, 2009).

Physical health

People with PMLD have "complex" healthcare needs (Bellamy, et al., 2010; Mansell, 2010; Pawlyn & Carnaby, 2009). The research literature describes a range of conditions that people with PMLD are said to be particularly prone to, including epilepsy (Arvio & Sillanpää, 2003; Hinder & Perry, 2000); respiratory problems (Wallis, 2009; Zijlstra & Vlaskamp, 2005); gastro-oesophageal reflux disease (Van Der Heide et al., 2009); sleep disorders (Jan & Freeman, 2004); fractured and broken bones

(Glick et al., 2005); pressure sores (Carnaby, 2004); malnourishment (Emerson, 2005; Ganesh et al., 1994); constipation (Veugelers, 2010); incontinence (Pawlyn & Budd, 2009), and dysphagia (Harding & Halai, 2009). People with PMLD may be technology-dependent and require oxygen, suctioning equipment, and nasogastric or gastrostomic tubes for feeding (Carnaby, 2004). Research has also suggested people with PMLD have poor oral health (Hulland & Sigal, 2000). Their lifestyles are described as being sedentary (Jones et al., 2007), leading to problems with posture, muscle strength, muscle tone, and bone metabolism (Lancioni et al., 1999; Pfister et al., 2003). Research has often reported that people with PMLD die significantly younger than people without learning disabilities. For example, a national study in the UK reported that people with PMLD are three times more likely to die as young adults than people without learning disabilities (Tyrer et al., 2007). A different study explored the premature deaths of people with learning disabilities in south west England and found that "the age at death decreased with increasing severity of learning disabilities … Essentially, the more severe a person's learning disabilities, the younger they were likely to die" (Heslop et al., 2013, p. 26).

Despite the growing literature documenting the aetiology and prevalence of medical conditions in the PMLD population, their lack of access to appropriate healthcare is a continuing concern. For example, treatable conditions sometimes go undiagnosed (Meehan, 1995). It has been suggested that this is partly because people with PMLD are denied access to screening services and check-ups (Burtner & Dicks, 1994; Hutchinson, 1998; PMLD Network, 2001). Problems also emerge when people with PMLD struggle to communicate their symptoms easily, such as the type and nature of pain (Davies & Evans, 2001). Behavioural expressions of pain can be idiosyncratic and unique to individuals (Van Der Putten & Vlaskamp, 2011). Consequently, the literature advocates that health professionals rely on non-verbal assessment (such as checklists) combined with expert judgement as well as carer intuition, though interpretation of symptoms can still be difficult for some, and it is believed that children may have learned to live with significant amounts of pain (Carter et al., 2002; Regnard et al., 2007). Another continuing concern is how to assess the sensory abilities of children with PMLD. Some researchers have attempted to use multisensory environments (MSEs) during assessment (Van Der Putten et al., 2011), whilst others combine behavioural and physiological measurement to assess

the sensory responsiveness of children with PMLD (Lima et al., 2012). Checklists have been devised but sometimes their reliability is in doubt, and the intimate knowledge of familiar others such as teachers has proved more fruitful (Vlaskamp & Cuppen-Fonteine, 2007).

In addition to assessment, other major barriers to healthcare include the negative attitude of some health professionals and a lack of specialist skills and resources to care for people with PMLD. In the UK a series of reports has documented parents' experiences of the ways doctors question the quality and value of life for people with PMLD (Mansell, 2010; Mencap, 2001; 2004). It is argued that this has contributed towards delayed treatment, suffering, and premature deaths (Heslop et al., 2013; Mencap, 2007; Michael, 2008). By contrast, recent research has demonstrated how nurse specialists draw from medical knowledge, common sense and intuition to provide comfort for people with PMLD who experience terminal illness (Ng, 2011), and there has been a call for instigating reflexive practice in nurses with regards to interpreting the meaning of behaviour of people with PMLD (Phelvin, 2013).

Mental health

Depression is said to be a common problem for people with intellectual disabilities but the mental health of people with PMLD has often been overlooked (Carpenter, 2004; Hogg, 1999). Diagnosing conditions like depression in people with PMLD can be challenging since formal assessments typically require verbally articulate people who can self-report their symptoms. In the absence of self-reporting, a diagnosis has to be made based on behavioural manifestations of a mental health problem, but this may prove to be difficult if observers fail to grasp the meaning of behaviour and lack confidence to make inferences about mental health (Fergusson et al., 2008). Furthermore, behavioural expressions of depression are not recognised by many standard diagnostic manuals (Hermans & Evenhuis, 2010) meaning that health professionals may lack the necessary tools to make a diagnosis in the first place. Several observation schedules have been designed that aim to assess constructs such as mood in people with PMLD, but these have been criticised for lacking validity and reliability (Ross & Oliver, 2003) or they lack research into the robustness of the schedules by people not involved in their design (Liu, 2007). In the search for alternative methods to explore mental health problems, researchers have explored physiological

change (e.g., endocrine output, vital signs, and temperature) to identify situations that people with PMLD may find stressful (Janssen et al., 2002). Other literature has advocated using interpersonal approaches to become familiar with the non-verbal behaviours of people with PMLD and to potentially "tune in" to their meaning and communicative intent (Sheehy & Nind, 2005). The role of carers who know people with PMLD intimately can be essential to the process of monitoring changes in behaviour indicative of mental health. However, there are reports that the observations of those who know people with PMLD best are not always taken seriously (Fergusson et al., 2008). Despite innovations in the field the complexity of personal, political, social and environmental factors of assessment are rarely recognised (Carnaby, 2007).

Children with PMLD are said to regularly engage in challenging, self-injurious behaviour, though in one study support staff were not inclined to rate such behaviours as a problem (Poppes et al., 2010). It has been suggested that such challenging behaviours result from the inability of people with PMLD to develop strategies to cope with stress (Janssen et al., 2002). One way of treating mental health disorders is to prescribe psychoactive medication (Lim, 2007; Kwok & Cheung, 2007). Some people with PMLD taking antipsychotic medications may experience adverse side effects such as akathisia (or "restless leg syndrome"). Akathisia is a movement disorder and the symptoms are said to include a sense of restlessness and a strong urge for motor activity. In the most severe cases people may experience uneasiness, anxiety, and irritability (Garcia & Matson, 2008). Non-medical interventions to improve the mental health of people with PMLD have also been explored. For example, research has suggested that exercise can reduce unhappiness in people with PMLD (Green & Reid, 1999b). Multisensory storytelling has also been used to help people with PMLD cope with sensitive issues (such as reducing fear of seizures or of equipment used by dentists) (Young et al., 2011).

The role of the family

The role and importance of the family of children with PMLD has been acknowledged in the literature. Children with PMLD can be heavily reliant on families, particularly parents, for basic care needs (e.g., eating, dressing, toileting) (Tadema & Vlaskamp, 2010). Historically, there has

been criticism for the lack of support families receive given the sheer volume of physical and emotional demands that "parent carers" may experience (Mencap, 2001; 2003; 2006; Withers & Bennett, 2003). The ongoing care routines that parents engage in can prevent them from seeking and gaining employment (Gordon et al., 2007). Research has explored the emotional complexities and ambiguous sense of loss that parents experience when their children are placed in out-of-home care (Roper & Jackson, 2007). Parents may feel particularly anxious if authorities offer out-of-borough placements (Jaydeokar & Piachaud, 2004). Some want to see their older children living in their own home, perhaps with a companion, and with twenty-four hour care and support (Fitton et al., 1995).

Families are also described as rich sources of information regarding the needs and abilities of children with PMLD. Family members should work alongside, or at least inform, professionals involved in their children's education, support, and care (Brett, 2002; Jansen et al., 2012). The literature has increasingly positioned parents as central to their children's cognitive development (Kurani, 2009) and communication development (Wilder, 2008). Despite the acknowledgement of parental expertise in the literature, there is also a body of work concerned with improving the knowledge and skills of parents (De Geeter et al., 2002). For example, one study identified the difficulties that parents experienced when trying to identify "high points" in the narratives of children's lives (Grove, 2007). The researcher theorised that the difficulty may have emerged from the interplay between children's lack of verbalisation about past events, and parents focus on the mundane care routines which are said to be punctuated by painful memories. Thus, where this is the case, there is a need to foster engaging experiences, recording of narratives, and the development of collaborative storytelling skills involving parents.

Deinstitutionalisation and community participation

Research has explored different models of care and accommodation for people (mainly adults) with PMLD, particularly in light of the development of community-based services as alternatives to institutional care. This research is typically framed in relation to how alternative settings support different levels of engagement (e.g., leisure time and social interaction), how different settings afford opportunities for people with

PMLD to develop functional skills or reduce challenging behaviour, and the impact of staff training on these issues (Felce & Emerson, 2001; Hiemstra et al., 2007; Mansell, 2006; Vlaskamp et al., 2007a; 2007b). The costs of quality care have also been explored (Emerson et al., 2000; Hatton et al., 1995) and research has advocated the need to present and maintain subjective histories for people transitioning to community care, such as the continued production of life story books (Hewitt, 2000a).

A related issue concerns the extent to which people with PMLD are not just deinstitutionalised in the sense of residential relocation, but how such relocation brings with it richer forms of community participation. Literature reviews in the field have cast doubt on the extent to which such participation actually occurs, since most empirical work fails to define and theorise what community participation means for people with PMLD (Verdonschot et al., 2009). Friendship is said to be a key factor that differentiates community placement from community participation (Clement & Bigby, 2009), but questions have been raised about the meaning of friendship for people with PMLD, particularly when such individuals are denied agency and thus said to lack the capacity to interact with others in reciprocal ways (Hughes et al., 2011).

Education: schooling

In recent years the United Kingdom has witnessed a rise in children with special educational needs and disabilities attending mainstream schools—learners who have traditionally been educated in segregated, specialist schools and units. The impetus for such change has largely come from legislation in the form of the Special Educational Needs and Disability Act (SENDA) (OPSI, 2001). SENDA has enshrined children's access to mainstream provision and made the refusal of access on the grounds of a child's impairment difficult. However, a report to the House of Commons has supported the general view that inclusive education may only go so far and that full-time mainstream placements for some children are unrealistic (Education & Skills Committee, 2006). Similarly, Baroness Warnock has challenged the extent to which inclusion can be achieved for all, and has championed a future and ongoing role for special schools (Warnock, 2005). The views of the House of Commons Select Committee and of Baroness Warnock are continuous with the Special Educational Needs Code of Practice (SENCOP) (DfES,

2001). SENCOP falls into a familiar governmental policy pattern of emphasising the need for inclusive education for most children whilst reinforcing the segregation of a selected few (Croll & Moses, 2000). Specifically, SENCOP describes how local education authorities must comply with parents' preference of school unless the school is unsuitable to the child's ability or would be incompatible with the education of other children in that school.

Children with PMLD are part of the group for which inclusive education is sometimes deemed unsuitable and unrealistic. It is argued that such children do not have the cognitive capacity to meaningfully engage with standard learning environments; that mainstream teachers lack the knowledge and skills required to support the development of children with PMLD, and that only special schools house the appropriate infrastructure and resources that children with PMLD require (Ainscow & Haile-Giorgis, 1998; Chesley & Calaluce, 1997; Foreman et al., 2004). More recently, it has been reasserted that people with PMLD need separate and distinct pedagogies (Imray, 2012) and individualised curriculums (Rayner, 2011). Rather than being included within mainstream schools, a commonly proposed model for children with PMLD is one of "inclusion" in a mixed-ability class within existing special school provision (Ouvry, 1986; Pratchett, 2004; Simmons & Bayliss, 2007). Despite resistance to inclusion there are examples which buck the trend, such as the London Borough of Newham which closed down most of its special schools and offered full-time mainstream placements to children in the UK with PMLD (Alderson, 1999). Currently, the majority of children with PMLD (82%) attend special schools. The rest attend mainstream primary schools (15%) or secondary schools (3%) (Salt, 2010). However, these figures do not indicate whether placement is full-time or part-time and, as discussed previously, estimating the number of children and adults with PMLD in the UK is open to debate. It is also important to note parental perspectives of inclusion. Whilst there is a dearth of research on this topic, one older study reported that parents of children with severe learning disabilities (SLD) and PMLD were satisfied with their specialist provision and did not want their children placed elsewhere (Male, 1998).

Very little research has been published which sheds light on the nature of inclusive education for children with PMLD, perhaps owing to the fact that such children are typically educated in special schools. Studies have explored online modules for training inclusive teachers